

Chronic Disease in Virginia Pregnancy Associated Deaths, 1999-2012: Need for Coordination of Care

A REPORT FROM THE VIRGINIA MATERNAL MORTALITY
REVIEW TEAM

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VIRGINIA MATERNAL MORTALITY REVIEW TEAM

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Mission Statement

Virginia's Maternal Mortality Review Team is dedicated to the identification and review of all pregnancy-associated deaths in the Commonwealth and the development of interventions that reduce preventable deaths.

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Table of Contents

INDEX OF TABLES AND FIGURES	iii
Index of Figures.....	iii
Index of Tables	iii
EXECUTIVE SUMMARY	iv
Key Findings on Chronic Disease in Pregnancy-Associated Deaths in Virginia	iv
Introduction	1
Overview	1
Purpose	1
Literature Review	2
Chronic Medical Conditions in Pregnancy-Associated Deaths	2
Coordination of Care in Pregnant Women with Chronic Medical Conditions	3
Methods.....	4
Results.....	5
Demographics and Causes of Death	5
Key Pregnancy Indicators and Risk Factors.....	6
Prevalence of Chronic Diseases	7
Factors Contributing to Mortality in Cases with a Chronic Disease.....	9
Coordination of Care.....	12
Discussion.....	13
TEAM RECOMMENDATIONS	14
Conclusion.....	18
References	20
Appendix A: Definitions	22
Appendix B: Chronic Disease Categories	24
Appendix C: Demographic Tables	25
Appendix D: Map of Maternal Mortality Rates by Health Planning Region	27
Appendix E: Summary of manner, cause of death, substance misuse and obesity of each chronic disease category	28
Appendix F: Provider Utilization Tables.....	30
Appendix G: Virginia Maternal Mortality Review Team Membership.....	32

INDEX OF TABLES AND FIGURES

Index of Figures

Figure 1: Number and Rate of Pregnancy-Associated Deaths by Year in Virginia, 1999-2012.....	1
Figure 2: Differences in Key Pregnancy Indicators among Cases with and without Chronic Conditions	7
Figure 3: Prevalence of chronic diseases among cases with at least one chronic disease.....	8
Figure 4: Percent of women with a facility-related factor contributing to their death, 1999-2012	10
Figure 5: Percent of women with a community-related factor contributing to their death, 1999-2012... ..	10
Figure 6: Percent of women with a provider-related factor contributing to their death, 1999-2012	11
Figure 7: The Team determined that a provider-related failure to refer or seek consultation contributed to mortality in a significant number of women with a chronic condition	12

Index of Tables

Table 1: Maternal deaths by chronic disease status in Virginia: Selected demographic characteristics, 1999-2012 (N=628)	25
Table 2: Summary of demographic variables for each chronic condition	26
Table 3: Summary of manner, cause of death, substance misuse, and obesity for each chronic condition category	28
Table 4: Provider utilization prior to and during pregnancy for each chronic condition category	30
Table 5: Referrals received, completed, and continued to see during pregnancy for each chronic disease category	31

EXECUTIVE SUMMARY

Virginia’s Maternal Mortality Review Team (the Team) was established in 2002 as a partnership between the Virginia Department of Health’s Offices of the Chief Medical Examiner and Family Health Services. The Team collects data on and reviews the deaths of all Virginia residents who were pregnant within a year of death regardless of the outcome of the pregnancy or the cause of death. These deaths are termed “pregnancy-associated deaths (PADs)”. Over the 14 years of case review, the Virginia Maternal Mortality Review Team noted the significance of chronic diseases in relation to mortality in pregnant women. As such, the Team elected to prepare this report, examining the trends and exploring chronic disease among PADs in Virginia and worked to identify risk factors associated with such deaths. This report focuses on women with chronic diseases (including chronic mental health and substance abuse issues) that died a PAD in Virginia between 1999 and 2012. These deaths include all manners of death (natural, homicide, suicide, accident, and undetermined).

The purpose of this work was to examine the prevalence of chronic diseases and co-morbidities in cases of PAD, identify gaps in the coordination of care received by women during their prenatal and post-partum period and to present the Virginia Maternal Mortality Review Team’s consensus recommendations developed to address coordination of care needs in pregnant and post-partum women with chronic diseases. Identifying and exploring the coordination of care efforts and needs among this group of women aided in understanding coordination of care in this population and highlight areas for improvement.

Key Findings on Chronic Disease in Pregnancy-Associated Deaths in Virginia

- Between 1999 and 2012, 427 women with a total of 848 chronic diseases died from a PAD in Virginia.
- The most prevalent chronic diseases were endocrine disorders, including obesity (43.8%), chronic mental illness (35.8%), and chronic substance abuse (29.6%).
- The number of chronic diseases present in each case of PAD ranged from 1 to 7 with a median of 2 chronic diseases.
- Overall, most women with a chronic disease died a natural death. Only women with chronic substance abuse had a higher percentage of non-natural deaths.

- Over 62% of women with at least one chronic condition died 6 weeks or more, post-birth.
- Only 36% of women with known chronic substance abuse had substance misuse or abuse identified as a risk in their medical record during their prenatal care.
- Over 50% of women with cardiovascular diseases, endocrine disorders, hematologic malignancy and/or pulmonary disease were obese.
- Only 34% of women with a chronic disease were seeing a provider to manage their chronic disease prior to pregnancy. Of those women who were seeing a provider prior to pregnancy, 72.4% continued to see that provider throughout the duration of their pregnancy.
- Just over 25% of women with a chronic disease received a referral to a specialist for management of their chronic disease(s) during pregnancy. Among those who received a referral, 84% completed the referral.
- Among women with at least one chronic disease, 44% had at least one provider-related factor¹, such as a failure to refer or seek consultation, contribute to their death

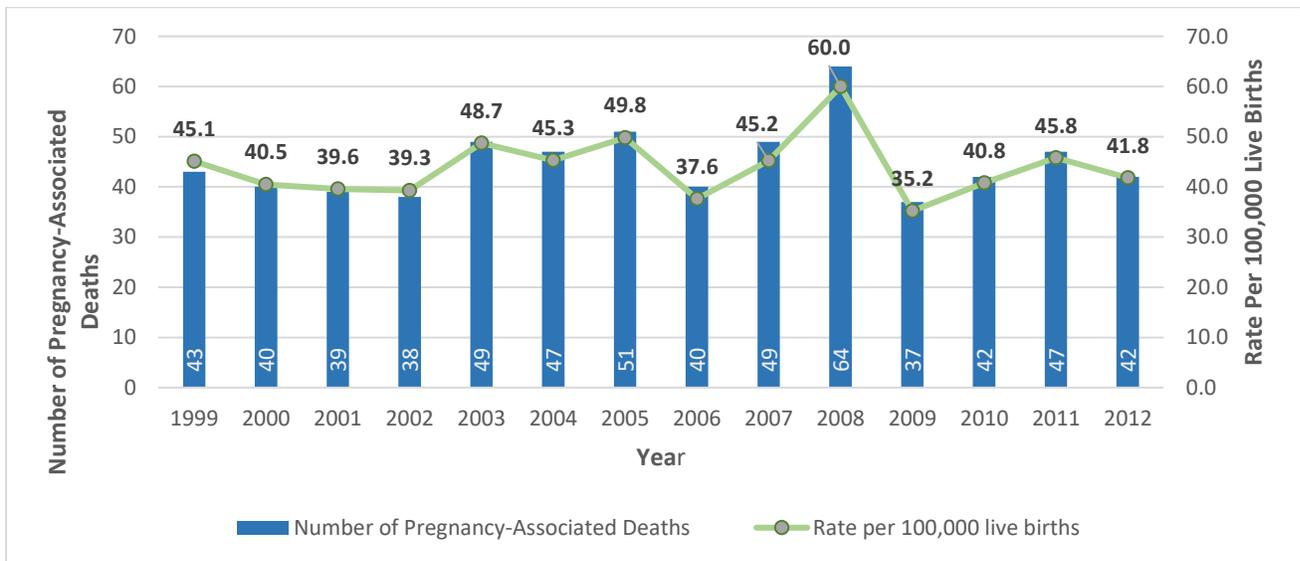
¹ Provider-related factors are factors associated with the care and/or treatment provided by a healthcare provider to individual patients. Examples include use of ineffective treatment, misdiagnosis, failure to refer or seek consultation and failure to screen for risk.

Introduction

Overview

Virginia’s Maternal Mortality Review Team (the Team) was established in 2002 as a partnership between the Virginia Department of Health’s Offices of the Chief Medical Examiner and Family Health Services. The Team collects data on and reviews the deaths of all Virginia residents who were pregnant within a year of death regardless of the outcome of the pregnancy or the cause of death. These deaths are termed “pregnancy-associated deaths (PADs)”. Between 1999 and 2012, 628 women died of a PAD in Virginia. The overall maternal mortality rate² was 43.9 during this period. Figure 1 shows the number and rate of PADs in Virginia over the thirteen-year period. The number and rate of deaths varied from year to year with no single pattern suggesting a clear increase or decrease over time.

Figure 1: Number and Rate of Pregnancy-Associated Deaths by Year in Virginia, 1999-2012



Purpose

The purpose of this work was to examine the prevalence of chronic diseases and co-morbidities in cases of pregnancy associated deaths (PADs), determine if there were gaps in the coordination of care received by women during their prenatal and post-partum period and to present the Virginia Maternal Mortality Review Team’s consensus recommendations to address

² Rate provided is the Maternal Mortality Rate (MMR), which is calculated by dividing the number of deaths in a category by the number of live births and then multiplying that number by 100,000. The MMR is the standard measure for evaluating maternal mortality.

coordination of care needs in pregnant and post-partum women with chronic diseases. Identifying and exploring the coordination of care efforts and needs among this group of women aided in understanding coordination of care in this population and highlighted areas for improvement.

Literature Review

Chronic Medical Conditions in Pregnancy-Associated Deaths

A recent report from the World Health Organization (WHO) identified that the maternal mortality rate in the United States more than doubled from 12 deaths per 100,000 live births in 1990 to 28 deaths per 100,000 in 2013 (World Health Organization & UNICEF, 2015). Several community, patient, healthcare professional and healthcare facility factors have been shown to contribute to maternal mortality over the years (Centers for Disease Control, 2017). These factors range from inadequate access to care to poor assessment of risk by the healthcare professional to a patient's lack of financial resources. Among patient factors, the increasing prevalence of chronic diseases, such as hypertension, diabetes and obesity among pregnant women (and among women of childbearing age), contributed significantly to the increase in the maternal mortality rate (Agrawal, 2015). Evidence shows that chronic disease affects 27% of all pregnant women and is related to an increase in post-partum emergency room visits (Kuklina, Ayala, & Callaghan, 2009). These conditions contribute to pregnancy-related complications and adverse reproductive health outcomes such as Cesarean delivery, eclampsia, perinatal infections, increased health care utilization and, ultimately, pregnancy-associated deaths (Chappell, Enye, Seed, Briley, Poston, & Shennan, 2008).

In addition to chronic medical conditions, chronic mental illness and substance abuse issues contribute significantly to maternal mortality (Agrawal, 2015). Chronic mental illness may be an underlying factor that contributes to suicide, accidental deaths, and deaths due to homicide (Centers for Disease Control, 2018; Wan, Morabito, Khaw, Knudson, & Dicker, 2006). Chronic mental illnesses may also contribute to maternal mortality in other ways, such as influencing an individual's compliance with treatment regimens for other chronic diseases (Centers for Disease Control, 2017). Chronic substance abuse also contributes to maternal mortality in several ways including late entry into prenatal care, poor adherence to health care

appointments and treatment regimens, inappropriate weight gain or loss during pregnancy, and increased sedation, intoxication, withdrawal and/or erratic behavior (Agrawal, 2015; Virginia Department of Health, 2015).

Coordination of Care in Pregnant Women with Chronic Medical Conditions

Increases in the prevalence of chronic diseases in women of childbearing age and the impact on maternal outcomes in recent years demonstrate the importance of and need for coordinated health care both prior to pregnancy and during the prenatal, perinatal and postpartum period (Chappell, et al., 2008). Coordination of care is the deliberate organization of patient care activities between two or more participants (including the patient) involved in a patient's care to facilitate the appropriate delivery of health care services (Shojania , McDonald, Wachter, & Owens, 2007). Adequate coordination of care can result in improved patient outcomes by ensuring that the patient is able to receive timely and effective care that meets their individual needs and preferences.

Recent evidence has shown that there are several obstacles within the American health care system that must be overcome in order to better coordinate care for pregnant women. These obstacles include disjointed health care systems with policies that vary among and between care sites, lack of communication between providers in multiple systems, a lack of coordination in patient management between providers, and the absence of policies and procedures that facilitate coordination of care and difficulties in completing consultations and/or referrals (Agency for Healthcare Research and Quality, 2018; Agrawal, 2015).

Problems in completing consultations and/or referral can occur for several reasons. Among them are a lack of patient understanding of why they are being referred and how to schedule appointments, as well as, specialists not consistently receiving clear reasons for the referral and adequate information on what has already been done so that there is no duplication of efforts (Agency for Healthcare Research and Quality, 2018). Amongst PADs in Virginia, the prevalence of the provider-related factors *“delay in or lack of diagnosis, treatment, or follow-up”* and *“failure to refer or seek consultation”* suggest that coordination of care related to provider utilization prior to pregnancy and referrals received during pregnancy contributed significantly to these deaths.

Methods

The Virginia Maternal Mortality Review Team has been using the methods set forth in the Center for Disease Control and Prevention's *Strategies to Reduce Pregnancy-Related Deaths* to collect data, conduct maternal mortality reviews and to utilize the data to develop recommendations to reduce maternal mortality (Berg, Danel, Atrash, Zane, & Bartlett, 2001). Mortality review is grounded in public health with a focus on prevention. These reviews involve in-depth examination of the circumstances surrounding death and provide a theory and method for identifying and understanding risk factors within a population. Maternal mortality review functions to improve understanding of all factors influencing the problem so that recommendations and interventions can be developed to reduce maternal deaths. Mortality review involves collecting and examining records generated through the investigation of a fatal illness or injury, and in this case, pregnancy-associated death.

Several methods were used to identify cases of PAD in Virginia. First, the Virginia State Vital Records Office identified cases of pregnancy-associated death in three categories: (1) examining the death certificate check box related to pregnancy status; (2) reviewing death certificate cause of death indicating death was directly attributable to pregnancy; and (3) matching death certificates of women of reproductive age with birth and fetal death certificates to identify deaths occurring among women who delivered in the year preceding death. Additional cases were also identified through the Virginia Violent Death Reporting System (VVDRS)³. Using information obtained from the death certificates, birth certificates, and fetal death certificates and the VVDRS, the review team identifies and requests records or abstracts records from the hospital where the birth or pregnancy occurred, birth attendants records, hospital records where the death occurred, autopsy records and the Medical Examiner case investigation records. As records from the initial requests are received, they are reviewed for any additional healthcare providers the woman may have seen, as well as, other services received such as social services, court and legal services, mental health services and/or addiction treatment services received. Any available records are then requested and collected from the additional health care providers and specialists, law enforcement agencies, social service agencies, and mental health facilities identified.

After the identification of all cases, demographic variables, including race, age, body mass index, insurance status, key pregnancy indicators, risk factors, and the presence of chronic diseases (see

³ The Virginia Violent Death Reporting System is the operation and reporting system of the National Violent Death Reporting System (NVDRS) within the state of Virginia. The NVDRS is a public health data system designed to better understand the breadth and scope of fatal violence and its victims and to support data driven violence prevention efforts.

Appendix B for chronic disease categories) were identified. The Virginia Maternal Mortality Review Team then reviewed each case to determine contributors to mortality and preventability of the death. Among cases for which a chronic disease was identified, records were also reviewed to determine provider utilization for the treatment of the disease, including seeing the same provider prior to and during pregnancy, referrals received during pregnancy, referrals completed during pregnancy, and referred providers who continued to treat the patient throughout the duration of their pregnancy. Pregnancy-associated mortality rates were calculated using birth certificate data and the standard definition of deaths/100,000 live births.

Results

Demographics and Causes of Death

There were several demographic similarities and differences between pregnancy associated death cases when at least one chronic condition was present and those in which there were no chronic diseases (See Appendix C). In both groups, white women died more frequently than black women. However, the maternal mortality rates highlighted significant racial disparities among black women with at least one chronic condition having a rate over twice that of their white counterparts (51.4 versus 25.1, respectively). Over 20 percent of those with a chronic condition were aged 30 and over compared to less than 14 percent of those without a chronic condition. For both those with and without a chronic condition, the highest percentage of women resided in the Eastern Health Planning Region (HPR) at 32.8% and 29.9%, respectively (See Appendix D). However, the maternal mortality rate for those in the Eastern HPR with a chronic condition (60.5) is more than twice as high as the rate for those without a chronic condition (25.3).

Women with a chronic condition also differed from women without a chronic condition on manner of death, cause of death, and the interval between the end of the index pregnancy and death (See Appendix E). Among women with a chronic condition, over 58% had a natural death compared to just over 45% of women without a chronic condition. The leading causes of death among those with a chronic condition include accidental overdose (14.1%) and cardiac disorders (12.9%). Accidental overdoses can occur from prescription medications, such as anti-anxiety medications, opioids, including methadone, as well as illegal drugs. Among those without a chronic condition, the leading causes of death were more violent including motor vehicle

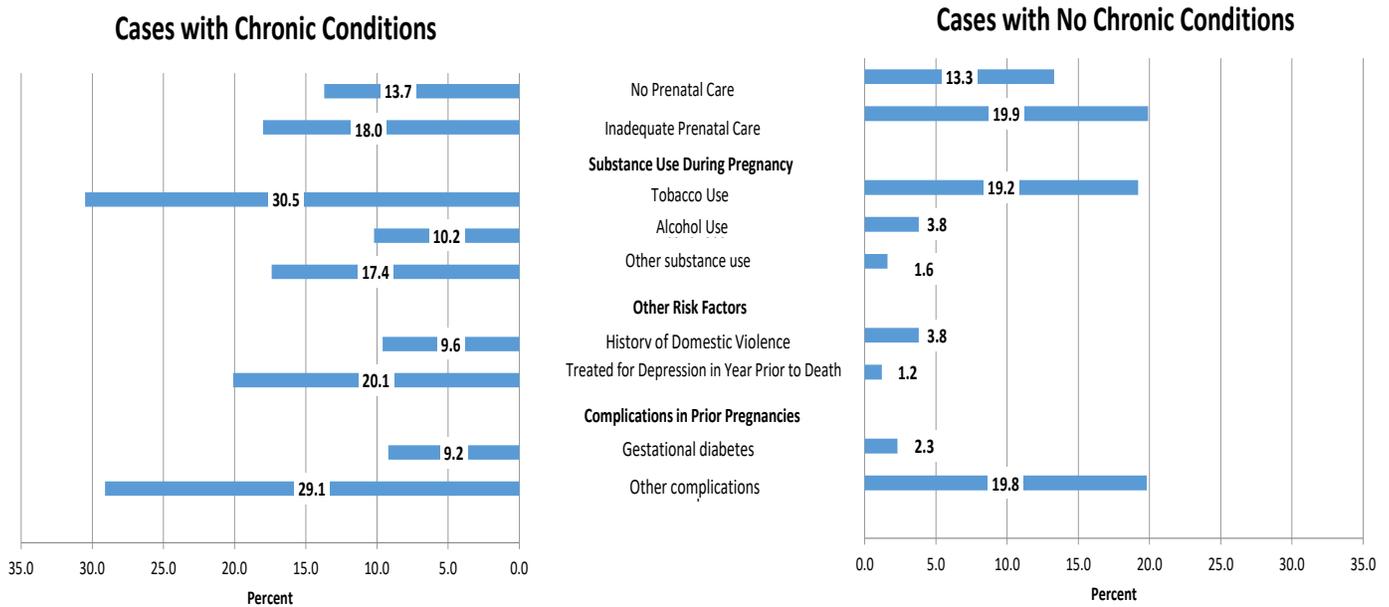
accidents (24.2%) and gunshot wounds (9.9%). Women with a chronic condition were more likely to have died after the postpartum period had ended; with 62.3% of these women dying 43 or more days following the end of the index pregnancy compared to just 42.3% of women without a chronic condition. This highlights the importance of continued management of a woman's health beyond the postpartum period especially among women with chronic conditions.

Key Pregnancy Indicators and Risk Factors

Significant differences also exist between women with a chronic condition and women without a chronic condition in relation to key pregnancy indicators and risk factors (Figure 2). Prenatal care utilization was similar among women with a chronic disease and their counterparts with only a slightly higher percentage of women without a chronic condition having inadequate prenatal care based on the Kotelchuck Index for Prenatal Care⁴. A higher percentage of women with a chronic condition, however, had other key pregnancy-risk indicators, such as a higher likelihood of using tobacco, alcohol or another substance not as indicated or prescribed during their pregnancy. These women also had a higher percentage of instances of domestic violence and treatment for depression in the year prior to their death. In addition, the percentage of women with a chronic condition with a history of gestational diabetes in a prior pregnancy was over 3 times as high as the percentage for women without a chronic condition.

⁴ The Kotelchuck Index for Prenatal Care determines the adequacy of a mother's prenatal care history based on when the woman initiated her prenatal care and the number of actual prenatal visits compared to the number of expected prenatal visits as determined by when prenatal care began and the time of delivery or end of pregnancy. Prenatal care can be classified as inadequate (receiving less than 50% of expected visits), intermediate (50%-79% of expected visits), adequate (80%-109% of expected visits) or adequate plus (110% of expected visits or more).

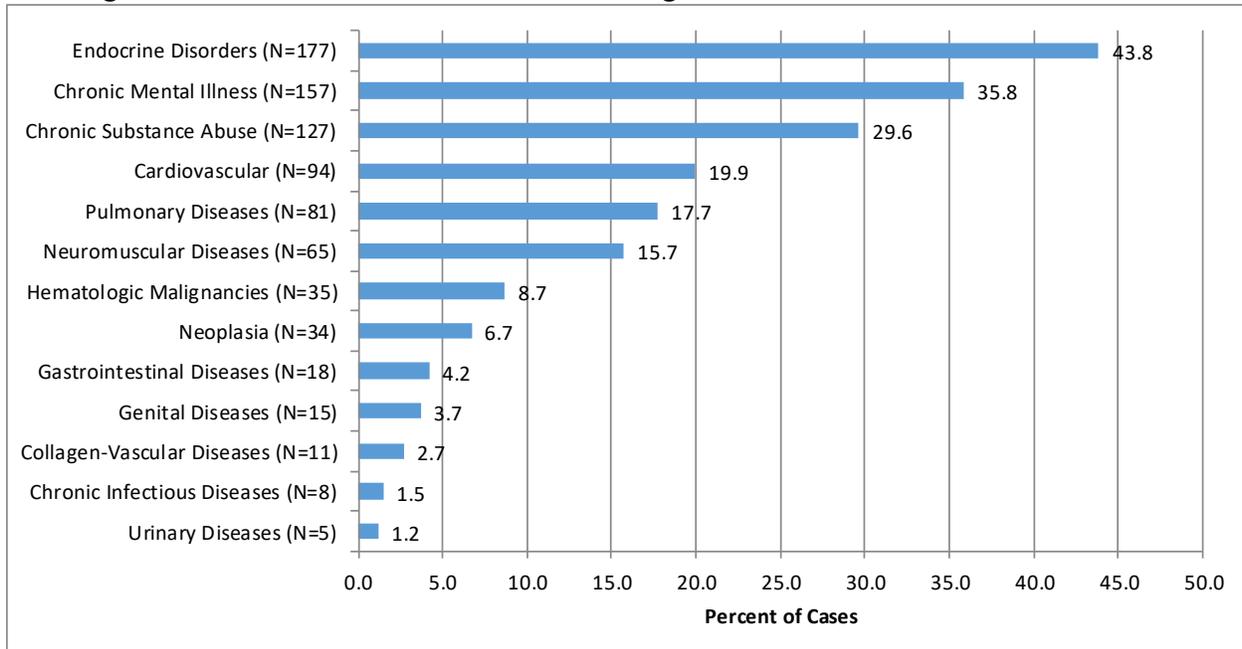
Figure 2: Differences in Key Pregnancy Indicators among Cases with and without Chronic Conditions



Prevalence of Chronic Diseases

Between 1999 and 2012, over two-thirds of women experiencing a pregnancy-associated death in Virginia had at least one diagnosed chronic condition. There were 427 women with a total of 848 chronic diseases. The number of chronic diseases in these women ranged from one to seven with a median of 2. Over 70% of these women were determined to have two or more chronic conditions. The most prevalent chronic diseases included endocrine disorders, chronic mental illness and chronic substance abuse (Figure 3). The most common endocrine disorders were obesity and diabetes. Co-morbidities among this group tended to follow similar patterns. For example, it is not uncommon to see a woman with an endocrine disorder who also had a cardiovascular disease and/or a mental illness. Among those with chronic substance abuse, over 50% also had a mental illness. Additionally, just over 45% of women with a pulmonary disease also had an endocrine disorder.

Figure 3: Prevalence of chronic diseases among cases with at least one chronic disease



Demographic variables differed among the various chronic disease categories (See Appendix C). Women with a cardiovascular disease had a higher percentage of advanced maternal age in comparison to the other disease categories with over 35 percent of the women being age 35 and older. For most of the chronic disease categories, white women were the most common race. However, black women were the most common race for those with infectious diseases, hematologic malignancies, pulmonary diseases and urinary diseases. The Eastern Health Planning Region (HPR) was the most common region for many of the chronic disease categories (32.0%) followed by the Central region (23.8%) which was the most common region for women with infectious diseases, mental illnesses, substance abuse, and urinary diseases. Women with infectious diseases, mental illnesses, substance abuse, neuromuscular diseases, and pulmonary diseases had a higher percentage with public insurance while women with collagen-vascular diseases, hematologic malignancies, neoplasia and urinary diseases had a higher percentage with private insurance.

Most women with a chronic condition died a natural death. Only women with chronic substance abuse had a higher percentage of deaths from a non-natural cause most of which were accidental deaths, including accidental overdoses and motor vehicle accidents. Examining the most common causes of death among women with chronic diseases revealed that women with

mental illnesses, substance abuse, neuromuscular diseases and pulmonary diseases were more likely to have died from an accidental overdose than other causes of death. Women with cardiovascular diseases, collagen-vascular diseases and endocrine disorders were more likely to have died from a cardiac disorder. Chronic conditions caused or contributed to the deaths in over 50 percent of women with a cardiovascular, infectious disease, substance abuse, collagen-vascular diseases and neoplasia. Only 36 percent of women with known chronic substance abuse had substance misuse identified as a risk during their prenatal care. Over 50 percent of women with a cardiovascular disease, endocrine disorder, hematologic malignancy and/or pulmonary disease were obese⁵.

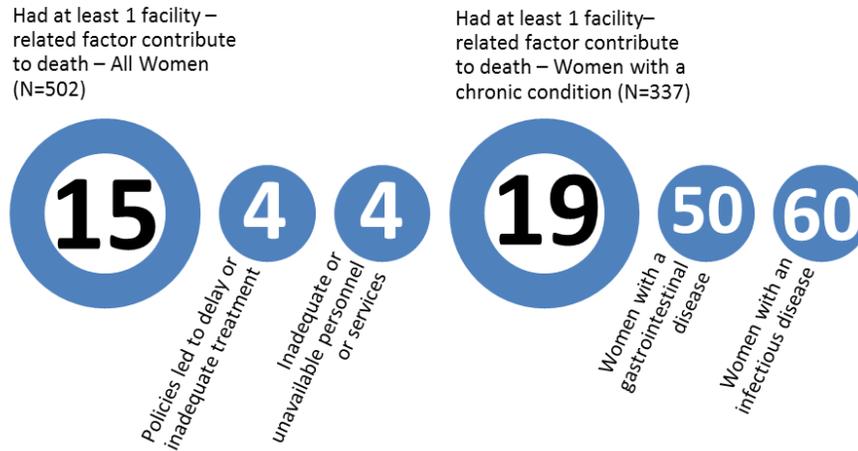
Factors Contributing to Mortality in Cases with a Chronic Disease

All pregnancy-associated deaths occurring in Virginia from 1999-2008 and 2012 have been reviewed by the Team⁶. As a part of each review, the committee assesses several community, facility, and provider related factors that contributed to each death. These reviews uncovered that 15% of all PADs had at least one facility-related factor contribute to the death (Figure 4). Facility-related factors refer to the individual facility's infrastructure, policies, and the availability of personnel, equipment, and technology. Examples of facility-related factors include *"policies led to delay or inadequate treatment (4%)"* and *"inadequate or unavailable personnel or services (4%)." Among women with a chronic condition, 19 percent had a facility-related factor contribute to their death. Facility-related factors were most prevalent in women with a gastrointestinal disease (50%) and those with an infectious disease (60%.*

⁵ Nearly 5 percent of women with a cardiovascular disease and 7 percent of women with an endocrine disorder were considered super-obese with a BMI greater than or equal to 50.0.

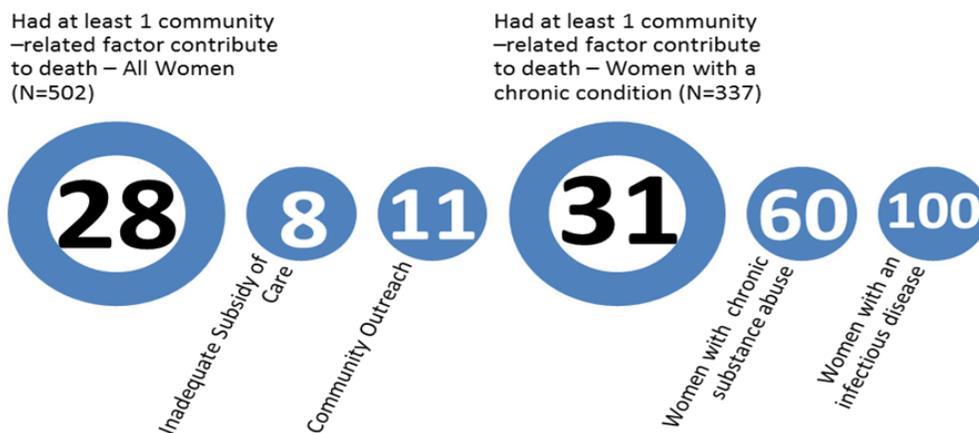
⁶ In 2015, the Maternal Mortality Review Team was in the process of reviewing 2008 cases. At this time, the Team realized that since 2008 there had been numerous policy changes that could affect maternal mortality in the state of Virginia, including the passing of the Affordable Care Act. The team determined that it was necessary to improve the timeliness of the case reviews so that the recommendations made by the Team would be more appropriate given current health policies. In an effort to be timelier with our case reviews, the Team elected to skip the review of cases from 2009 to 2011. While the team did not review individual cases from these years, data from these cases are included in the Maternal Mortality Database. This lack of Team review for these cases is a limitation in the data.

Figure 4: Percent of women with a facility-related factor contributing to their death, 1999-2012



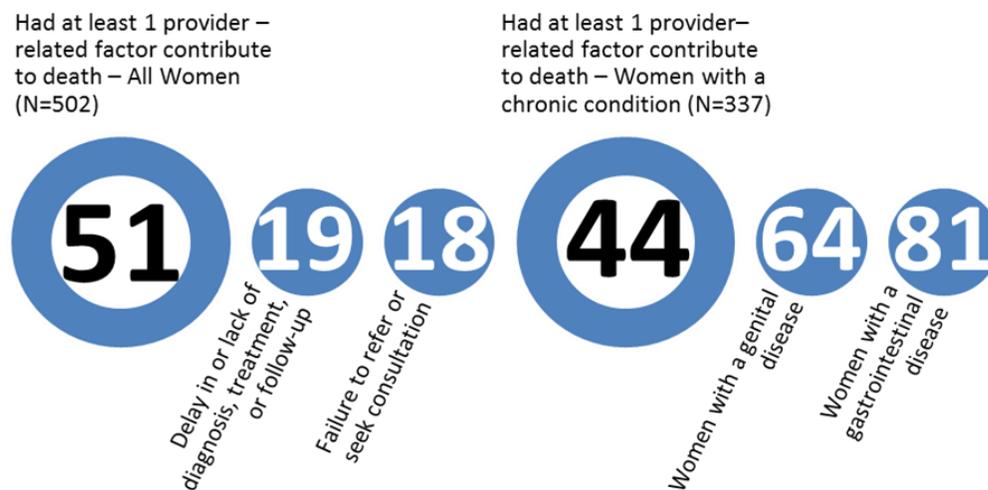
Community-related factors involve the availability and accessibility of services in the community, law enforcement response, community outreach and availability of subsidized care. Twenty-eight percent of all PADs had a community-related factor contribute to the death (Figure 5). Eight percent of women had “*inadequate subsidy of care*” such as being ineligible for Medicaid or prescription drug assistance services. While, 11 percent were found to have “*inadequate community outreach*,” including a lack of health education campaigns, contribute to death. Among women with a chronic condition, 31 percent had a community-related factor contribute to death. Community related factors were most prevalent among women with chronic substance abuse and those with an infectious disease.

Figure 5: Percent of women with a community-related factor contributing to their death, 1999-2012



Provider-related factors are factors associated with the care and/or treatment provided by a healthcare provider to individual patients. Provider-related factors were the most prevalent contributors to mortality amongst all PADs (51%) and amongst only women with a chronic condition (44%) (Figure 6). The most prevalent provider-related contributors to mortality include “delay in or lack of diagnosis, treatment or follow-up” (19%) and “failure to refer or seek consultation” (18%). Women with a genital disease or a gastrointestinal disease had the highest percentage of provider-related factors contributing to mortality at 64% and 81%, respectively.

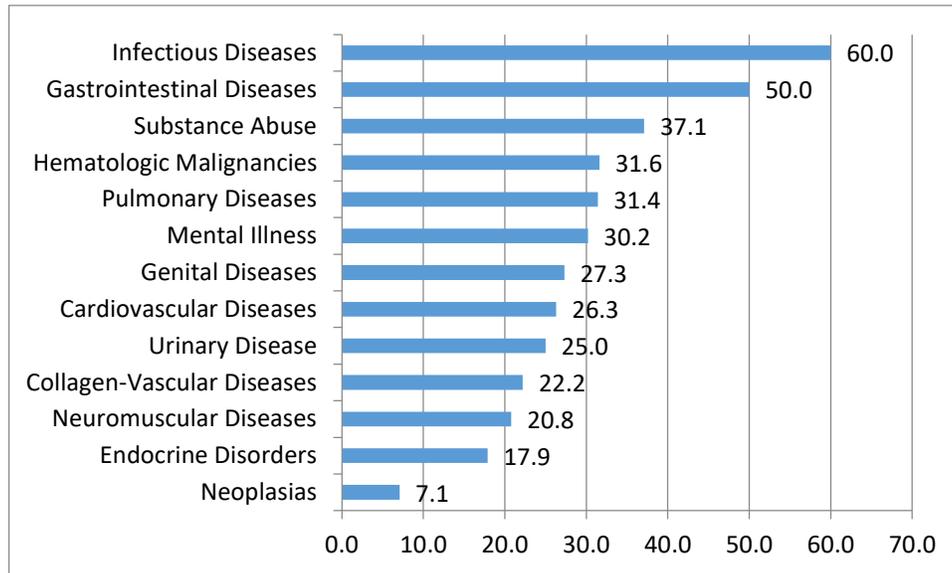
Figure 6: Percent of women with a provider-related factor contributing to their death, 1999-2012



Among women with chronic conditions, referrals and consultations are important for the appropriate management of these chronic conditions during pregnancy, the postpartum period and beyond. Figure 7 shows the percentage of women within each chronic disease category for which the Team determined a failure to refer or seek consultation contributed to the death. A failure to refer or seek consultation was most significant amongst women with a chronic infectious disease (60.0%) or a gastrointestinal disease (50.0%). In addition, over 30 percent of women with substance abuse, hematologic malignancies, pulmonary diseases and/or mental illnesses had a failure to refer or seek consultation contributing to their death. In contrast, women with a neoplasia were least likely to have a failure to refer or seek consultation contribute to their death (7.1%) suggesting that coordination of care for women with a neoplasia is more

often adequate and may provide the model for which coordination of care for women with other disease categories should be based.

Figure 7: The Team determined that a provider-related failure to refer or seek consultation contributed to mortality in a significant number of women with a chronic condition



Coordination of Care

The prevalence of provider-related factors related to a failure to refer or seek consultation and delays in diagnosis, treatment or follow-up suggests that coordination of care, particularly related to provider utilization, consultations and referrals, is an important issue among pregnant women in Virginia and contributes significantly to PAD. Approximately one third of women with a chronic condition were seeing a provider to manage their chronic condition prior to pregnancy (see Appendix F). Women with hematologic malignancies were more likely to be seeing a provider prior to pregnancy (71.4%) while women with gastrointestinal diseases were least likely to be seeing a provider prior to pregnancy (27.8%). While only 32 percent of women with a neoplasia were seeing a provider prior to pregnancy, 100 percent of those women continued to see that provider throughout their pregnancy. One hundred percent of women with an infectious disease and genital disease continued seeing the provider they were seeing prior to and throughout their pregnancy. Women with urinary diseases (50.0%), substance abuse (56.3%) and/or cardiovascular diseases (57.4%) were least likely to continue seeing their pre-pregnancy provider throughout the duration of their pregnancy. In addition, only 61% of women with a

mental illness and 63% of women with a pulmonary disease continued to see a provider they had seen prior to pregnancy.

Overall, just over 25 percent of women with a chronic condition received a referral to a specialist or other provider during their pregnancy (See Appendix F). Women with pulmonary diseases and collagen-vascular diseases were the least likely to be referred to a specialist at 7.4 and 9.1 percent, respectively. Women with a neoplasia were most likely to receive a referral (44.1%) followed by women with a urinary disease (20.0%) or chronic substance abuse (18.9%). Among women who received a referral, those with chronic substance abuse were least likely to complete the referral as ordered (41.7%) followed by women with a pulmonary disease (50.0%) or mental illness (56.0%). Women with an infectious disease, collagen-vascular disease, gastrointestinal disease, genital disease, hematologic malignancy, neoplasia and urinary diseases completed 100% of their referrals. Women with a pulmonary disease or gastrointestinal disease had the lowest percentage of women who completed a referral with a provider that continued to see that provider throughout the remainder of her pregnancy (33.3% and 50.0%, respectively). One hundred percent of women with an infectious disease, collagen-vascular disease, genital disease, hematologic malignancy or neoplasia that completed a referral to a specialist during their pregnancy continued to see that provider throughout the remainder of their pregnancy.

Discussion

The Virginia Maternal Mortality Team's review of pregnancy-associated deaths between 1999 and 2012 revealed that nearly 70 percent of all women experiencing a pregnancy-associated death had at least one chronic condition. The number of chronic diseases in these women ranged from one to seven with a median of two. The most prevalent chronic diseases include endocrine disorders (43.8%), chronic mental illness (35.8%), chronic substance abuse (29.6%) and cardiovascular diseases (19.9%). Over 45 percent of women with a chronic disease had public insurance that only provided coverage during pregnancy and the 6 weeks post-partum. The data shows that incomplete healthcare coverage outside of pregnancy (prior to becoming pregnant and after the post-partum period) is a contributor to maternal mortality in Virginia. This is particularly important in light of the fact that over 62 percent of women with a

chronic condition died after the 6-week postpartum period (between 43 and 365 days of pregnancy termination).

The analyses in this report also highlights a lack of provider utilization for management of chronic diseases prior to pregnancy and a lack of referrals to specialists during pregnancy amongst women experiencing a PAD in Virginia. Team review of PAD cases suggests that there is a “hands off” dynamic seen in relation to the coordination of care in pregnant women with the care and management of chronic diseases in these women often being left up to the obstetrician. Additionally, many pregnant women were often treated in Emergency Departments and then left to navigate referrals and other services on their own with little to no coordination of care.

The results of this report highlight several opportunities for the prevention of PADs among women with chronic diseases and the improvement of the coordination of care in this group. Improving the management and coordination of care for chronic diseases in pregnant women requires not only a refined approach to the clinical care of pregnant women but also strategies that can be deployed at the practice- and system-level of care delivery. These strategies should include policy changes, educational campaigns, and training that address issues surrounding chronic disease in pregnancy, including: the lack of routine health care for chronic conditions outside of pregnancy (both prior to pregnancy and after the post-partum period), limited availability of specialists and women’s health providers in rural areas, and the need for the provision of nutrition and dietician services in pregnancy due to the high prevalence of obesity in this group. The interoperability of medical records is also important with this patient population as it will allow specialists and emergency room providers to have access to important, time-critical medical information that can help to improve patient care at the point of service. Implementing strategies that address these issues is critical to the improvement of health outcomes and the prevention of pregnancy-associated deaths among pregnant women with chronic diseases.

TEAM RECOMMENDATIONS

Given the portrait of chronic diseases and pregnancy-associated mortality, pre-conception care and routine health care for every woman of childbearing age is critical. Data from the team review reveals that many chronic health conditions are not adequately addressed prior

to pregnancy, during the pregnancy and post-partum period (from delivery to 43 days post-delivery) and beyond. The data also reveals that there is a lack of coordination of care with many women not receiving the appropriate screenings, referrals and/or being left to navigate the complicated health care system on their own. There is a need for a system of affordable, coordinated care that is institutionalized in the U.S. as a cultural value, a medical standard of care and a human right. Women's health is part of a system of care that includes women and their families, their communities, standard practices and institutions. Improving the health outcomes of pregnant women with chronic diseases involves changes at the community, provider, facility and system level.

The following recommendations were developed by the Virginia Maternal Mortality Review Team in fulfillment of its mission and in honor of the women who died and from whom the Team are privileged to have learned these lessons. The Team hopes the information published in this report along with its recommendations will be used in the continued effort to prevent PADs among women in Virginia. Recommendations are organized by topic area and also grouped by the agencies or association that would be best equipped to implement the recommendation(s) presented.

Provider and Public Education:

1. Virginia Board of Medicine

- a.** All healthcare providers licensed by the Board of Medicine should be required to receive and maintain training (through continuing medical education requirements) in the contemporary management of chronic diseases in women of childbearing age within the scope of practice in their specialty.
- b.** All providers of care to women of childbearing age should be trained in and engage in Screening, Brief Intervention and Referral to Treatment (SBIRT) for substance abuse, mental illness, domestic violence and trauma at the initiation of care.

2. Department of Health Professions

Given that women with chronic diseases have worse outcomes during pregnancy and the postpartum period, we recommend that board certifiers promote and incentivize

the use of established prescribed management algorithms for standards of care for the treatment of pregnant and postpartum women through required Continued Medical Education. These should include the management of hypertension, heart failure, and hemorrhage.

3. Virginia Neonatal Perinatal Collaborative

A strategic outreach plan should be developed and implemented in partnership with other appropriate organizations to educate the public on the issue of maternal mortality and morbidity. This outreach plan should include highlighting the role of chronic disease management in the prevention of maternal mortality. A fact sheet about chronic diseases and maternal mortality should also be developed and distributed.

Services Provided:

5. Virginia Hospital and Healthcare Association

- a. Every hospital should identify and clearly list a designee at that hospital with training in women’s health and perinatal care to provide care or consultations for pregnant women, as necessary. If that individual is not available or there is no provider at the hospital with training in women’s health and perinatal care, the hospital should establish a protocol and develop ongoing relationships with a location and/or provider for consult and or referral. This would include establishing a relationship with a tertiary care center for regional support and/or identifying and clearly listing providers available via telephone access for consultations and referrals.
- b. All emergency departments should have processes and policies in place to ensure that care coordination occurs for all pregnant patients at the time of discharge. This care coordination should include identification of barriers to care and follow-up care, referrals to community resources to help address these barriers, and communication with the follow-up providers to ensure that providers are aware of the referrals.

- c. There are several geographic areas/regions where specialist services for consultations for chronic diseases in obstetric patients are not available. Existing telemedicine services should be utilized to increase access to specialist services and consultations in those areas.
- d. There is a need for interoperability/sharing of medical records needed for the treatment of a pregnant patient from the time of conception throughout the end of the postpartum period. The Virginia Maternal Mortality Review team supports the efforts of the Virginia Hospital and Healthcare Association state-wide task force on the interoperability of medical records.

Health Insurance Coverage:

- 6. Virginia Legislature
 - a. Coverage for women enrolled in the Virginia FAMIS program during pregnancy should be expanded to provide increased access to comprehensive coverage for chronic disease management, including substance abuse treatment (both residential and outpatient), mental health services and family planning.
 - b. All insurance plans should be required to cover nutrition and dietician services for women of reproductive age by a registered dietician, as needed. Among pregnant women, covered nutrition and dietician services should include a minimum of one comprehensive initial assessment and one follow-up appointment per pregnancy trimester. Telemedicine services should be utilized in areas in which a registered dietitian is not available.

Further Study:

- 7. Virginia Department of Health.

A task force should be created to discuss the problem of chronic diseases in relation to maternal mortality and the roles of individual specialties in the care and management of chronic diseases in pregnant and postpartum women. In addition, the task force should develop algorithms for standards of collaborative care. This task force should include, at a minimum, the Medical Society of Virginia, Virginia Chapter of the American College of Cardiology, Virginia College of Emergency Physicians,

Virginia Association of Hematologists and Oncologists, Society of Critical Care Medicine, Virginia Chapter of the Association of Women's Health, Obstetric and Neonatal Nurses, the Virginia Affiliate of the American College of Nurse Midwives, the Virginia Chapter of the National Association of Social Workers and the Virginia Academy of Nutrition and Dietetics.

Conclusion

The data presented in this report reveals that chronic diseases are an important issue among women who experienced a pregnancy-associated death. Over two-thirds of the cases included in this report had at least one chronic disease with a significant portion of women having two or more chronic diseases. Most of these women were determined to have died a natural death 43 days or more following the end of their pregnancy. Inadequate provider utilization prior to pregnancy and inadequate coordination of care during and after pregnancy was determined to contribute significantly to these deaths by the Maternal Mortality Review Team. Less than 40 percent of the cases included in report were seeing a provider to manage their chronic condition prior to pregnancy with only 72 percent continuing to see that provider throughout their pregnancy. In addition, only 25 percent of women with a chronic disease received a referral to a specialist for the management of their chronic condition during their pregnancy.

There are several opportunities for the improvement of the coordination of care and management of chronic diseases in pregnant women highlighted in this report. Among them are increasing provider and specialist training in the management of specific chronic conditions in pregnant women and improving the accessibility of women's health specialists in emergency departments and nutrition and dietetic services. Additionally, implementing policies that facilitate the coordination of care and patient navigation, inclusive of the identification of barriers to care and the provision of referrals to community resources to address the identified barriers, is important.

Improving the health outcomes of pregnant women with chronic diseases is a complex problem that must involve changes at the patient, community, provider, facility and system level. It is the hope of the Virginia Maternal Mortality Review Team that the information presented in this report and the recommendations made will be useful in the continued efforts to improve

health outcomes among pregnant women in Virginia and to reduce the number of pregnancy-associated deaths

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World Health Organization & UNICEF. (2015). *Trends in maternal mortality: 1990 to 2013. Estimates by WHO, UNICEF, UNFPA, The World Bank and the United Nations Population Division*. Geneva: World Health Organization.

Appendix A: Definitions

Accidental Overdose: When a person unintentionally takes more of a substance than is medically recommended. Overdoses can occur from both prescription medications and illicit drugs.

Chronic Diseases: A human health condition or disease that is persistent or otherwise long-lasting in its effects or a disease that comes with time. The term chronic is usually applied when the course of the disease lasts for more than three months. For the purposes of this report, both chronic mental illness and chronic substance abuse have been included as chronic diseases.

Cardiovascular Diseases: Diseases that involve the heart or blood vessels.

Chronic Infectious Diseases: Communicable illnesses prolonged in duration that do not resolve spontaneously and are rarely cured completely.

Chronic Mental Illness: A mental illness or psychiatric disorder, is a diagnosis by a mental health professional of a behavioral or mental pattern that may cause suffering or a poor ability to function in life. Such features may be persistent, relapsing and remitting

Chronic Substance Abuse: A chronic, relapsing disorder characterized by compulsive drug seeking, continued use despite harmful consequences, and long-lasting changes in the brain.

Collagen-Vascular Diseases: Any of a group of inflammatory diseases, often autoimmune diseases, affecting the connective tissue.

Endocrine Disorders: Disorders of the endocrine system, involving the production of too much or too little of an endocrine hormone or the development of lesions (such as tumors or nodules) in the endocrine system.

Gastrointestinal Diseases: Diseases involving the gastrointestinal tract, namely the esophagus, stomach, small intestine, large intestine and rectum, and the accessory organs of digestion, the liver, gallbladder, and pancreas.

Genital Diseases: Illnesses that occur when the genital organs are not functioning properly.

Hematologic Malignancies: Cancers and illnesses that affect the blood and lymph system.

Neoplasia: Atypical and excessive cell growth that results in an abnormal tissue mass or tumor.

Neuromuscular Diseases: Diseases that affect the muscles and/or their direct nervous system control.

Pulmonary Diseases: Diseases affecting the lungs.

Urinary Diseases: Illnesses that occur when the urinary organs are not functioning properly.

Coordination of Care: The deliberate organization of patient care activities between two or more participants (including the patient) involved in a patient's care to facilitate the appropriate delivery of health care services. Organizing care involves the marshalling of personnel and other resources needed to carry out all required patient care activities, and is often managed by the exchange of information among participants responsible for different aspects of care.

Manner of Death: The fashion or circumstances that result in death, which are designated either natural or unnatural. Unnatural deaths are designated as accidental, homicidal, suicidal, or, in absence of a determination based on the balance of probabilities of the manner of death, undetermined.

Pregnancy-Associated Death: The death of a woman while pregnant or within one year of pregnancy regardless of the outcome of the pregnancy or the cause of death.

Pregnancy-Associated Rate: Calculated by dividing the number of pregnancy-associated deaths by the number of live births for the same time period and multiplying by 100,000. The rate provides the number of deaths for every 100,000 live births to women who were residents of the state at the time of their deaths. Rates for Race, Age, and Health Planning Region (HPR) are category specific. Rates for Manner and Cause of Death are overall rates/100,000 live births.

Pregnancy-Related Death: The death of a woman during pregnancy or within one year of the end of pregnancy from a pregnancy complication, a chain of events initiated by pregnancy, or the aggravation of an unrelated condition by the physiologic effects of pregnancy.

Appendix B: Chronic Disease Categories

1. **Cardiovascular Diseases**
 - a. Congestive heart failure
 - b. Heart disease
 - c. Heart palpitations
 - d. Hypertension
2. **Chronic Infectious diseases**
 - a. HIV
 - b. AIDS
3. **Chronic Mental Illnesses**
4. **Chronic Substance Abuse**
 - a. Alcoholism
 - b. Illicit drug abuse
 - c. Prescription drug abuse
5. **Collagen-Vascular Diseases**
 - a. Fibromyalgia
 - b. Scleroderma
 - c. Sjogren's syndrome
6. **Endocrine Disorders**
 - a. Diabetes
 - b. Grave's disease
 - c. Hypothyroidism
 - d. Morbid obesity
 - e. Polycystic ovaries syndrome
7. **Gastrointestinal Diseases**
 - a. Cholelithiasis
 - b. Crohn's disease
 - c. Chronic abdominal pain
 - d. Hepatitis C
 - e. Irritable bowel syndrome
8. **Genital Diseases**
 - a. Endometriosis
 - b. Endometritis
 - c. Uterine fibroids
9. **Hematologic Malignancies**
 - a. Acute lymphocytic leukemia
 - b. Acute myeloid leukemia
 - c. Anaplastic large-cell lymphoma
 - d. Anemia
 - e. Aplastic anemia
 - f. Burkett's lymphoma
 - g. Clotting disorder
 - h. Coagulopathy
 - i. Hodgkin lymphoma
 - j. Relapsing thrombocytopenia purpura
 - k. Sickle cell disease
 - l. T-cell lymphoma
10. **Neoplasia**
 - a. Breast cancer
 - b. Bronchogenic carcinoma
 - c. Cervical cancer
 - d. Glioblastoma
 - e. Melanoma
 - f. Mesothelioma
 - g. Ovarian cancer
 - h. Sarcoma
11. **Neuromuscular Diseases**
 - a. Amyotrophic lateral sclerosis
 - b. Bell's palsy
 - c. Chronic pain – general
 - d. Devic's disease
 - e. Epilepsy
 - f. Headaches/migraines
 - g. Multiple sclerosis
 - h. Pseudo seizures
12. **Pulmonary Diseases**
 - a. Asthma
 - b. Pulmonary fibrosis
 - c. Sarcoidosis
13. **Urinary Diseases**
 - a. Chronic kidney stones
 - b. Nephropathy
 - c. Polycystic kidney disease

Appendix C: Demographic Tables

Table 1: Maternal deaths by chronic disease status in Virginia: Selected demographic characteristics, 1999-2012 (N=628)

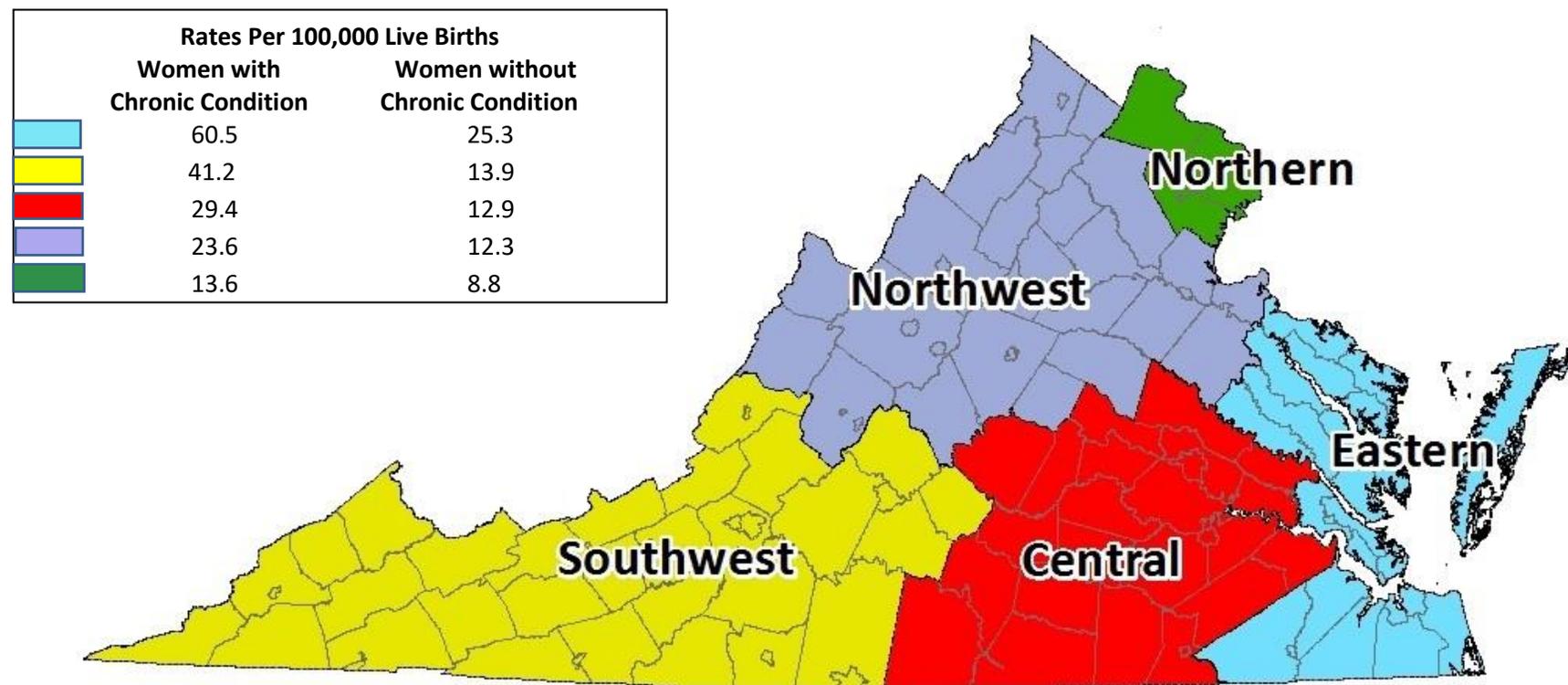
	No Chronic diseases (N=201)			Chronic diseases (N=427)		
	Number	%	Rate	Number	%	Rate
Demographics						
Race						
White	97	48.3	9.2	240	56.2	25.1
Black	86	42.8	27.4	164	38.4	51.4
Other	18	8.9	14.6	23	5.4	18.6
Ethnicity						
Hispanic	16	8.0	1.1	12	2.8	0.8
Not Hispanic	185	92.0	12.5	415	97.2	29.5
Age at Death						
19 and under	28	13.9	23.5	34	7.9	29.6
20-24	77	38.3	22.3	85	19.9	25.5
25-29	37	18.4	9.3	125	29.3	33.1
30-34	29	14.4	8.4	96	22.5	26.6
35-39	19	9.5	10.3	67	15.7	35.9
40 and above	8	4.0	17.0	20	4.7	48.6
Health Planning Region of Residence						
Central	45	22.4	12.9	100	23.4	29.4
Eastern	60	29.9	25.3	140	32.8	60.5
Northern	38	18.9	8.8	60	14.1	13.6
Northwest	27	13.4	12.3	47	11.0	23.6
Southwest	30	14.9	13.9	80	18.7	41.2
Source of Insurance						
Public (i.e. Medicaid)	67	33.3	4.7	193	45.1	13.4
Private	61	30.3	4.4	163	38.2	11.6
Unknown	33	16.4	2.5	38	8.9	2.8
Self-pay	23	11.4	1.7	25	5.9	1.9
No medical care	16	8.6	0.5	8	1.9	0.5
Total	201	100.0	13.7	427	100.0	30.2

Table 2: Summary of demographic variables for each chronic condition

Chronic Disease Category	Average Age	% Advanced Maternal Age	Most Common Race/Ethnicity	Most Common Health Planning Region	% with Public Insurance	% with Private Insurance	% with no insurance
Cardiovascular Diseases	31.9	35.4%	white	Eastern	40.1%	42.1%	17.8%
Collagen-Vascular Diseases	29.6	18.2%	white	Northern , Central, Eastern	18.2%	72.7%	9.1%
Endocrine Disorders	29.4	21.8%	white	Eastern	46.5%	44.0%	9.5%
Gastrointestinal Diseases	30.0	23.5%	white	Eastern	47.1%	35.3%	17.6%
Genital Diseases	30.9	20.0%	white	Northern	40.0%	60.0%	0%
Hematologic Malignancies	28.2	14.8%	black	Eastern	37.0%	59.3%	3.7%
Infectious Diseases	29.3	16.7%	black	Central	66.7%	0.0%	33.3%
Mental Illnesses	28.7	23.6%	white	Central	48.6%	29.6%	21.8%
Neoplasia	30.5	20.6%	white	Eastern	41.2%	55.9%	2.9%
Neuromuscular Diseases	28.6	19.7%	white	Eastern	49.2%	31.1%	19.7%
Pulmonary Diseases	27.8	18.3%	black	Eastern	50.7%	32.4%	16.9%
Substance Abuse	28.7	20.1%	white	Central	60.5%	13.4%	26.1%
Urinary Diseases	27.8	0.0%	black	Central	40.0%	60.0%	0%

Appendix D: Map of Maternal Mortality Rates by Health Planning Region

Figure 8: Map of maternal mortality rates by health planning region among women with and without a chronic disease



Appendix E: Summary of manner, cause of death, substance misuse and obesity of each chronic disease category

Table 3: Summary of manner, cause of death, substance misuse, and obesity for each chronic condition category

Chronic Disease Category	Most Common Manner of Death	Most Common Cause of Death	% Chronic Condition Caused or Contributed to Death	% with Substance Misuse Risk Identified in Prenatal Care	% Obese (BMI = 30.0 – 49.9)	% Super-Obese (BMI >= 50.0)
Cardiovascular Diseases	Natural	Cardiac Disorder (29.9%)	54.1%	10.1%	54.5%	4.5%
Collagen-Vascular Diseases	Natural	Cardiac Disorder (30.0%)	75.0%	9.1%	36.4%	0.0%
Endocrine Disorders	Natural	Cardiac Disorder (17.2%)	29.4%	8.8%	79.7%	7.0%
Gastrointestinal Diseases	Natural	Cardiac Disorder, Exacerbation of Chronic Disease (17.6%)	44.4%	23.5%	50.0%	0.0%
Genital Diseases	Natural	Poisoning (26.6%)	28.6%	20.0%	45.5%	0.0%
Hematologic Malignancies	Natural	Cardiac Disorder, Disorder of the Central Nervous System (12.5%)	41.7%	22.2%	52.4%	0.0%
Infectious Diseases	Natural	AIDS Related (66.7%)	66.7%	33.3%	0.0%	0.0%
Mental Illnesses	Natural	Accidental Overdose (22.5%)	47.4%	21.0%	35.5%	0.9%
Neoplasia	Natural	Cancer (88.2%)	88.2%	5.9%	29.6%	0.0%

Chronic Disease in Virginia Pregnancy Associated Deaths, 1999-2012: Need for Coordination of Care

Chronic Disease Category	Most Common Manner of Death	Most Common Cause of Death	% Chronic Condition Caused or Contributed to Death	% with Substance Misuse Risk Identified in Prenatal Care	% Obese (BMI = 30.0 – 49.9)	% Super-Obese (BMI >= 50.0)
Neuromuscular Diseases	Natural	Accidental Overdose (25.0%)	28.2%	9.8%	31.9%	0.0%
Pulmonary Diseases	Natural	Accidental Overdose (18.6%)	34.4%	16.9%	51.7%	1.7%
Substance Abuse	Accident	Accidental Overdose (32.8%)	76.3%	36.1%	26.3%	0.0%
Urinary Diseases	Natural	Pulmonary Embolism, Cardiac Disorder, Exacerbation of Chronic Condition (20.0%)	20.0%	20.0%	25.0%	0.0%

Appendix F: Provider Utilization Tables

Table 4: Provider utilization prior to and during pregnancy for each chronic condition category

Chronic Disease Category	Provider seen Prior to Pregnancy		Continued to see provider during pregnancy	
	N	%	N	%
Cardiovascular Diseases	47	50.0	27	57.4
Infectious Diseases	4	50.0	4	100.0
Mental Illnesses	70	44.6	43	61.4
Substance Abuse	55	43.3	31	56.3
Collagen-Vascular Diseases	6	54.5	5	83.3
Endocrine Disorders	63	35.6	44	69.8
Gastrointestinal Diseases	5	27.8	4	80.0
Genital Diseases	6	40.0	6	100.0
Hematologic Malignancies	25	71.4	20	80.0
Neoplasia	11	32.3	11	100.0
Neuromuscular Diseases	30	46.2	25	83.3
Pulmonary Diseases	32	39.5	20	62.5
Urinary Diseases	2	40.0	1	50.0
All Chronic diseases	145	34.0	105	72.4

Table 5: Referrals received, completed, and continued to see during pregnancy for each chronic disease category

Chronic Disease Category	Referral Received During Pregnancy		Completed Referral During Pregnancy		Continued to See the Referred Provider During Pregnancy	
	N	%	N	%	N	%
Cardiovascular Diseases	15	16.0	11	73.3	8	70.0
Infectious Diseases	1	12.5	1	100.0	1	100.0
Mental Illnesses	25	15.9	14	56.0	10	69.2
Substance Abuse	24	18.9	10	41.7	8	80.0
Collagen-Vascular Diseases	1	9.1	1	100.0	1	100.0
Endocrine Disorders	22	12.4	16	72.7	15	93.3
Gastrointestinal Diseases	2	11.1	2	100.0	1	50.0
Genital Diseases	2	13.3	2	100.0	2	100.0
Hematologic Malignancies	4	11.4	4	100.0	4	100.0
Neoplasia	15	44.1	15	100.0	15	100.0
Neuromuscular Diseases	8	12.3	6	75.0	5	83.3
Pulmonary Diseases	6	7.4	3	50.0	1	33.3
Urinary Diseases	1	20.0	1	100.0	1	100.0
Total	108	25.3	91	84.3	82	90.1

Appendix G: Virginia Maternal Mortality Review Team Membership

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